

AD _____

GRANT NUMBER DAMD17-94-J-4134

TITLE: Breast Health Education Study

PRINCIPAL INVESTIGATOR: Beverly D. Taylor, M.D.

CONTRACTING ORGANIZATION: Morehouse School of Medicine
Atlanta, Georgia 30310-1495

REPORT DATE: November 1998

TYPE OF REPORT: Final

PREPARED FOR: Commander
U.S. Army Medical Research and Materiel Command
Fort Detrick, Frederick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Approved for public release;
distribution unlimited

The views, opinions and/or findings contained in this report are those of the author(s) and should not be construed as an official Department of the Army position, policy or decision unless so designated by other documentation.

19990401 053

REPORT DOCUMENTATION PAGE

Form Approved
OMB No. 0704-0188

Public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to Washington Headquarters Services, Directorate for Information Operations and Reports, 1215 Jefferson Davis Highway, Suite 1204, Arlington, VA 22202-4302, and to the Office of Management and Budget, Paperwork Reduction Project (0704-0188), Washington, DC 20503.

1. AGENCY USE ONLY (Leave blank)		2. REPORT DATE November 1998	3. REPORT TYPE AND DATES COVERED Final (1 Jul 94 - 30 Jun 98)	
4. TITLE AND SUBTITLE Breast Health Education Study			5. FUNDING NUMBERS DAMD17-94-J-4134	
6. AUTHOR(S) Beverly D. Taylor, M.D.				
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) Morehouse School of Medicine Atlanta, Georgia 30310-1495			8. PERFORMING ORGANIZATION REPORT NUMBER	
9. SPONSORING/MONITORING AGENCY NAME(S) AND ADDRESS(ES) Commander U.S. Army Medical Research and Materiel Command Fort Detrick, Frederick, Maryland 21702-5012			10. SPONSORING/MONITORING AGENCY REPORT NUMBER	
11. SUPPLEMENTARY NOTES				
12a. DISTRIBUTION / AVAILABILITY STATEMENT Approved for public release; distribution unlimited			12b. DISTRIBUTION CODE	
13. ABSTRACT (Maximum 200) <p>Morehouse School of Medicine has developed a Breast Health Education Study that focuses on two groups:</p> <ol style="list-style-type: none"> 1.) minority, underserved women who are residents of Atlanta Housing Authority communities, and 2.) primary care physicians and other health care providers who care for the medically underserved. <p>The study seeks to determine and validate the efficacy of community-based educational program initiatives in promoting breast health in this population by educating and motivating target women to seek mammograms and perform breast self-examinations on a regular basis. We also seek to determine and validate the efficacy of an innovative educational initiative in encouraging other health professionals to discuss and promote clinical breast exams, mammographies and breast self-examinations to their female patients.</p> <p>During the second year of the study (FY 95-96), seven communities within the Atlanta Housing Authority were identified, along with community leaders, and informed of the project and encouraged to participate. Community Lay Health Workers (CLHW) who are also residents of the communities selected were hired, trained and are working in the community. Morehouse School of Medicine students in the Masters of Public Health Program as well as medical students were hired to assist the CLHW in the conduction of the breast health education community health needs assessment and baseline breast cancer knowledge, attitudes and practices assessment in each community. Two hundred men and women of various ages were randomly selected from community clusters to participate in the survey.</p> <p>INFODRAMA presentations (The Education Initiative for Health Professionals) were conducted at the Annual Meeting of the Atlanta Chapter of National Black Nurses Association and the 6th Annual Meeting of the National Black Leadership Initiative on Cancer, Southern Region. Preliminary results of the community assessment substantiate the need for breast health education programs if we are ever going to favorably impact the health of these communities.</p>				
14. SUBJECT TERMS Breast Cancer			15. NUMBER OF PAGES 49	
			16. PRICE CODE	
17. SECURITY CLASSIFICATION OF REPORT Unclassified	18. SECURITY CLASSIFICATION OF THIS PAGE Unclassified	19. SECURITY CLASSIFICATION OF ABSTRACT Unclassified	20. LIMITATION OF ABSTRACT Unlimited	

FOREWORD

Opinions, interpretations, conclusions and recommendations are those of the author and are not necessarily endorsed by the U.S. Army.

____ Where copyrighted material is quoted, permission has been obtained to use such material.

____ Where material from documents designated for limited distribution is quoted, permission has been obtained to use the material.

____ Citations of commercial organizations and trade names in this report do not constitute an official Department of Army endorsement or approval of the products or services of these organizations.


____ In conducting research using animals, the investigator(s) adhered to the "Guide for the Care and Use of Laboratory Animals," prepared by the Committee on Care and Use of Laboratory Animals of the Institute of Laboratory Resources, National Research Council (NIH Publication No. 86-23, Revised 1985).

✓
____ For the protection of human subjects, the investigator(s) adhered to policies of applicable Federal Law 45 CFR 46.

____ In conducting research utilizing recombinant DNA technology, the investigator(s) adhered to current guidelines promulgated by the National Institutes of Health.

____ In the conduct of research utilizing recombinant DNA, the investigator(s) adhered to the NIH Guidelines for Research Involving Recombinant DNA Molecules.

____ In the conduct of research involving hazardous organisms, the investigator(s) adhered to the CDC-NIH Guide for Biosafety in Microbiological and Biomedical Laboratories.


____ Signature _____ Date

11/16/98

TABLE OF CONTENTS

Introduction	4
Nature of the Problem	4
Background of Previous Work	5
Purpose of the Present Work	6
Methods of Approach	7
Body	8
Background, Sample and Data Collection	9
Results of the Post-Test Only Comparison Group Study	20
Results of the Infodrama Evaluation	28
Discussion	35
Recommendations	35
References	37
Bibliography	39
Appendix	

**FINAL REPORT FOR GRANT NO. DAMD17-94-J-4134
BREAST HEALTH EDUCATION STUDY**

INTRODUCTION

The Breast Health Education Study at Morehouse School of Medicine, received funding for a three-year cycle, by the Department of Defense in 1994. The purpose of the project was: to seek to determine and validate the efficacy of a community-based educational program initiative in promoting breast health in minority, medically under-served women by educating and motivating them to seek mammograms and perform breast self-examinations on a regular basis.

The grant proposal was revised on several occasions to accommodate changes in the demographic and geographic structure of the original communities identified for the focus of our intervention.

The study focuses on two groups to achieve its goals:

- 1) minority and under-served women, in the metropolitan Atlanta area, and
- 2) Family and primary care physicians and other health care providers who care for the medically under-served

Nature of the Problem:

African American women are more likely than white women to have advanced breast cancer and to have poor survival from those cancers.^{1,2,3,4} Although the incidence rate of breast cancer is lower in African American women than White women (94.0/100,000 vs. 113.20/1000,000); the mortality rate in this population is higher (31.2 vs. 27.2).⁵ Further, once diagnosed with breast cancer, African American women tend to have lower survival rates than White-American women.

The five year survival rate is 81.6% for whites but only 65.8% for Black women.⁵ This is thought to be due primarily to the more advanced stage of the disease at the time of diagnosis.^{6, 7,8,9}

Reasons for this advanced stage of disease has included limited access to health care and decreased use of mammographic screening⁸ as well as some socioeconomical and hormonal issues.

Many studies have been done to determine the reasons for low mammography use among African American women. Results have revealed that many women do not get mammograms because their physicians don't tell them that they need one, or make any references to them.^{9, 10,11,12} Lack of knowledge about the screening recommendations is another barrier to complying with

recommendations.^{13, 14, 15, 16} From these studies, it becomes clear that a two-tiered approach to promoting mammography screening among women is indicated.

This breast cancer education and prevention project attempts to address the three overall goals of Healthy People 2000: to increase the span of healthy life, to reduce health disparities, and to achieve access to preventive services for all Americans. Two preventive service objectives are also addressed: **Objective 16.3--** to reduce breast cancer mortality and **Objective 16.11--** to increase the proportion of women age 40 and older that received a clinical breast examination and mammogram. At least two Educational and Community-Based Program objectives are addressed: **Objective 8.1** which seeks to increase the years of healthy life of black people and **Objective 8.11** which emphasizes increasing culturally appropriate community health promotion programs for minority populations.¹⁷

Background of previous work:

The Atlanta Coalition on Breast Health was established in August 1990 by the Southern Region of the National Black Leadership Initiative on Cancer (NBLIC) to focus on the problem of breast cancer among black women in the Atlanta area. The Coalition has implemented as its major project, the Black Women's Mammography and Screening Project, a community education model developed by the National Medical Association's Council on Concerns of Women Physicians in cooperation with the Minority Health Education Program, Office of Cancer Communications, National Cancer Institute. A long-term goal of the NBLIC is to replicate the structure and activities of the Atlanta Coalition in other parts of Georgia and the region.

Since its establishment in August 1990, the Coalition has accomplished a number of important initiatives including:

- ▶ conducted over 12 mini Breast Health Education Workshops throughout Metro Atlanta and some parts of South Georgia. These workshops were attended by over 200 women between the ages of 18 and 65 years of age;
- ▶ development of a facility guide of Association of Certified Radiologists (ACR) approved mammography screening sites in the Atlanta area;
- ▶ development of a training curriculum for Coalition members. This "train the trainer" curriculum is designed to equip members with the skills needed to train community leaders and community members in breast cancer prevention;
- ▶ assisted in the training of Community Lay Health Workers assigned to the targeted communities;

- ▶ completion of the Breast Health Training Manual;
- ▶ distributed the training manual to community based programs as well as breast cancer researchers;
- ▶ participated in a one day workshop on implementation and planning conducted by Florence Bonner, a consultant with the National Cancer Institute;

The Atlanta Coalition participated in the planning and development of the Breast Health Education Study and continues to work in the remaining communities.

Purpose of the present work:

The purpose of this project is to impact favorably, the breast health of low income, under-served minority women. As stated previously, the project addresses three of the overall goals of *Healthy People 2000*:

- ▶ *to increase the span of healthy life*
- ▶ *to reduce health disparities, and*
- ▶ *to achieve access to preventive services for all Americans*

Two preventive services objectives are addressed:

- ▶ *Objective 16.3: to reduce breast cancer mortality, and*
- ▶ *Objective 16.11: to increase the proportion of women age 40 and older that has received a clinical breast examination and mammogram.*

And, two educational and Community-based program objectives:

- ▶ *Objective 8.1a: which seeks to increase the years of healthy life of black people, and*
- ▶ *Objective 8.11: which emphasizes increasing culturally appropriate community health promotion programs for minority populations.*

We believed that a culturally appropriate, comprehensive breast cancer screening intervention in a low-income public housing community would increase rates at which women obtain clinical breast examinations and mammogram. If successful, these rates will approach the frequencies recommended by the National Cancer Institute.

Methods of approach:

A review of recent literature and studies on promoting breast health makes it apparent that effective breast cancer prevention and early detection requires education of both health professionals and clients. For example, the Morehouse Cancer Screening Project entitled, "Avoidable Mortality from Cancer in Black Populations (AMCBP) targeted black women in the inner city. The study sought to determine if an in-home educational intervention conducted by a Lay-Health Worker could increase adherence among low-income black women to breast cancer screening schedules as well as increase the women's knowledge and change their attitudes regarding these cancers. The results of the study showed a 2.9% increase in Pap smear screening, and a 34.5% increase in breast screening. AMCBP's study method of educational intervention differs from those in the proposed project (in-home vs. Community group); however, the target group is the same and the proposed study emphasizes cultural appropriateness and is based on a philosophy of empowering low-income (blacks) to help themselves and one another.

The approach to community organization and development for health promotion for the communities in this study is based on the theories of Braithwaite, Lythcott et al,¹⁸ and call for the following steps:

- ▶ Learn the community
- ▶ Document the community ecology
- ▶ Organize a community coalition board
- ▶ Share the results with the community
- ▶ Design an intervention
- ▶ Implement the intervention

The problems encountered in recruiting participants in this study have been identified. The Study continued to be plagued by this problem resulting in suboptimal results for data analysis.

Our original plan was to do a case-comparison study using a series of before and after comparisons calculating the changes of adequate screening rates between the intervention group and the comparison group. Two hundred participants in each group would be surveyed. We identified cases and comparison groups who resided in high-rise complexes within the Atlanta Housing Authority (AHA); and case and comparison groups who resided in low-rise complexes. Each community within the cluster of communities was organized following the steps for community organization listed above. We had to change the method of analysis due to the difficulty we had in doing interventions and retrieving post-test data from the participants. We had to adjust the method of analyzing the data to accommodate the small sample size that was obtained.

We will use an experimental design using the post-test only comparison method of analysis for the community based portion of the study. The comparison group, residents who participated in the intervention and received the post-test will be compared to the control group, those residents who did not participate in the intervention and only had the post-test.

The approach to determine the breast health practices of primary care providers was through the development of an Infodrama. The Infodrama is a dramatic representation of information, in this case breast cancer prevention information, that provides the participant with valuable medical information. The research team developed the Infodrama with the assistance of a playwright with experience in developing and producing health-related skits. The presentation was designed to include the epidemiology, risk factors, barriers, current recommendations for screening, and treatment options for breast cancer. It also provided information on the affect the diagnosis has on the patient, the family and on the provider. A pre-test was administered prior to the presentation with a mailed post-test questionnaire six months later.

Problems with Implementation: We encountered several problems with implementation and completion of the study once the grant was received. These include:

- ▶ The original community withdrew from the study which required negotiation for another community. Six communities were selected with the assistance of the Atlanta Housing Authority (AHA)
- ▶ AHA initiates the dismantling of several communities. This included some of the study communities
- ▶ The epidemiologist of the study left Morehouse School of Medicine to take a position in Taiwan
- ▶ The lack of familiarity with the Infodrama format by conference planners resulted in poor placement of the presentation on the schedule, resulting in poor visibility of the intervention for conference participants
- ▶ Healthcare providers were hesitant to come to the presentation for fear of having to participate in the drama.

BODY

Methods

Background, Sample and Data Collection

The Breast Health Education Study is designed to focus on the consumers and the providers of breast cancer screening practices. It utilizes lay health workers to recruit and provide individual instruction to Black women on breast cancer prevention; and an Infodrama (dramatic presentation of information on breast cancer screening practices) geared for the health care provider.

The Community:

The women invited to participate in this project were residents of six public housing facilities and one Section VIII community that was managed by the Atlanta Housing Authority in Atlanta, Georgia. They were selected from two sources of housing communities: High- Rises, community housing for those residents who are disabled or are 62 years of age and older and/or disabled; and Low-rises, community housing for residents who are younger than 62 years of age. Women were eligible to participate in the intervention if they were aged 35-79, a current resident of an intervention community, and had no personal history of breast cancer or breast surgery.

A community survey was conducted to determine the knowledge base, attitudes and beliefs about cancer within the community. The information would be used to tailor the intervention to the needs of that population. Two hundred community surveys were completed. The members of the Atlanta Coalition on Breast Cancer developed and implemented the curriculum for the intervention.

The communities participating in this study are:

High Rises:

1. Antone Graves
2. Graves Annex
3. Martin Luther King,
4. Cosby Spears I/Cosby Spears II, and
5. John O. Childs

Low Rises:

1. Carver Homes
2. Villa Monte (Section 8 housing)

Two hundred survey instruments were completed which included 38 men. The questionnaire

surveyed the community's general knowledge of the community about cancer and included questions on breast, prostate, cervical cancer as well as questions on nutrition and cancer. For the purposes of this report we factored out the responses from men which gave us a breast cancer survey file of 162 women.

The Infodrama:

Several conferences for primary care providers were targeted for the Infodrama presentations. They are:

- ▶ Focus Group Presentation to Family Medicine Residents, Morehouse School of Medicine, Fall 1994
- ▶ Internal Medicine Noon conference, Grady Memorial Hospital, May 1995
- ▶ Georgia State Medical Association Annual Meeting, Hilton Head, South Carolina, June 1995
- ▶ Black Nurses of Georgia Association Regional Meeting, Atlanta, Georgia
- ▶ Georgia Academy of Family Physicians' Annual Conference, Westin Conference Center, Conference Center, Marietta Georgia. November 1996
- ▶ Advances in Primary Care, Practical Approaches for the African-American Patient, Sponsored by the Department of Family Medicine, Morehouse School of Medicine, April 1997

A specialist in breast cancer treatment reviewed the script for the Infodrama presentation prior to the initiation of the workshops.

A pre-test was administered prior to the initiation of the intervention with a mailed post-test survey six months later. During this past year of no-cost extension of the project, we attempted to enhance our response rate to the intervention by conducting two additional mailings followed by a telephone reminder to encourage the physician to complete with the questionnaire.

Specific objectives of the study were to:

1. Organize each intervention community around the problem of breast cancer

Communities within the Atlanta Housing Authority each have a Tenant Association. This organization is composed of residents within the community. It serves as the governing

body for the community by identifying and resolving issues related to safe and efficient living conditions. The residents of the community elect a Tenant Association President who serves as the point of entry into the community. The Tenant Association President is a very powerful person who has been given the "authority" to represent the community.

The Tenant Association President of each of the selected communities received a visit by the study team to present the Breast Health Education Project and solicit their support. They were all receptive but different in their approach to presenting the project to their constituents. In each case we were invited to attend a Tenant Association meeting where the president introduced us to the community. We introduced the project to the residents of the community. We were asked to present our program and were available to answer any questions they had.

We advertised for Community Lay Health Workers (CLHW) in each community. We successfully recruited six women to work with us. Their ages ranged from 35-79. They came from three of the six communities (two of the original six workers were discontinued and replaced from the pool of applications received during recruitment). These workers received training in breast cancer prevention through workshops conducted by the Atlanta Coalition on Breast Health. CLHW's, assisted by our staff, began to develop community coalitions, or groups of residents interested in breast cancer prevention, who would also receive the training and assist the CLHW's in providing support for other women within the community.

The CLHW was also responsible for assisting in the survey of 200 community members. Each CLHW served as the point person to recruit survey participants from our list of randomly selected candidates, and was paired with a trained interviewer (graduate student) to attend each interview. A presentation of the data obtained during this phase of the study will appear later in the report.

2. Conduct programs to improve breast cancer knowledge, attitudes, and screening practices among members of the intervention communities at large, health care providers serving these communities, and women aged 35-79 residing in these communities.

The second phase of the project at the community level was a series of workshops on breast health that was presented in the various communities. The workshops were designed to empower participants to become pro-active in preventing breast cancer. One of our purposes was to instill confidence in their knowledge about the disease; by teaching them what to do to assist in the early detection of breast cancer; and teaching them ways to effectively communicate with their health care provider. Efforts are made to

dispel the myths and misconceptions that some of them had regarding breast cancer.

A training Manual was developed in conjunction with the National Black Leadership Initiative on Cancer for the purpose of providing breast health education in a consistent manner. A copy of the manual was submitted with annual report submitted last year.

The second component of the Breast Health Education Study is the implementation and evaluation of an intervention that educates and motivates primary care physicians to discuss breast health issues with their patients. In the form of an Infodrama, an interactive dramatic production based on actual case histories, the intervention encourages primary care physicians to recommend regular breast self-examinations, clinical breast examinations and screening mammogram to their patients. The Infodrama was developed and produced by a local playwright in Atlanta, GA. with technical assistance from the Breast Health Education Study team. We used four professional actors for each performance.

The script for the presentation is based on research studies, information obtained from provider and consumer focus groups, and information pertaining to the social and cultural issues being explored. The impact of the presentation was assessed through pre- and post-intervention questionnaires that measured the physicians' knowledge, attitudes, and practices regarding breast health care. The pretest is given immediately prior to the Infodrama presentation. The post-test survey instrument mailed six months afterwards. Second and third mailings, followed by a telephone call, were done in an effort to increase the response rate.

3. Evaluate the impact of the comprehensive intervention on breast cancer screening, knowledge, attitudes, and practices.

The bulk of our work this year was done in retrieving post-test survey instruments and analyzing that data. We requested a no cost extension to provide us with the opportunity to finalize the data collected during the workshops and during the Infodrama presentations.

Person-to-person interviews were conducted between the spring of 1996 and the beginning of 1997 for the community survey. In an effort to determine the community's perception of cancer in general and breast cancer specifically, a random sample of 200 community residents were selected using the Atlanta Housing Authority tenants occupancy list. Men were not excluded from the community survey if they were members of the randomly selected household. This sample of 200 community survey participants was representative of who we wanted to include in this study.

Measures

Graduate students of the Morehouse School of Medicine administered a brief 20-30 minute structured questionnaire to the community survey participants. Each student received interviewing skills training prior to participation in the study. We paired each student with a Community Lay Health Worker (also a participant in the interviewing process). The Community Lay Health Worker (CLHW) was responsible for setting up the interview, reminding the participant of the interview appointment and was present, but not obtrusive, during the time of the interview.

The questions assessed sociodemographic characteristics, medical and family history, preventive health practices, insurance characteristics, level of exercise, weight control, tobacco use, alcohol use, cancer knowledge, attitudes, and beliefs, and history of breast cancer screening.

- **Sociodemographic** questions addressed marital status, level of education, employment history, what they believed to be the most important aspect of life, religious preference, income level and their opinion of their own personal health.
- **Knowledge and attitude** questions addressed personal susceptibility to breast cancer, whether a woman can have breast cancer with/without certain symptoms, whether cancer was a health problem in the community, and the likelihood of their attendance at breast health educational workshops.
- **History of breast cancer screening** addressed the frequency of the study participant receiving breast self-examinations, clinical breast examination, and mammography.

Data Analysis

During this past year we have attempted to complete the collection of data from the two groups targeted for our intervention. We have had considerable difficulty being successful in that effort and as a result have lost the power analysis needed to make significant assumptions in most comparisons.

Results:

The Community Lay Health Worker

The Breast Health Education Study (BHES) has as its focus, women living in inner city, under served communities and primary care physicians who provide care for these communities.

The community was organized with the assistance of the Community Lay Health Worker (CLHW), community members who lived almost exclusively in low income community settings, and who are trained to serve as translators between community participants, health care providers and project administrators. CLHW recruitment requirements included:

- Must complete a formal application,
- Must be a resident of one of the selected communities (for a minimum of 2 years),
- Must pass reading and writing proficiency tests, and
- Must participant in the interview process

The interview was required in order to give the interviewer some insight into the applicants' knowledge of the socio-economic, ecological, environmental and political concerns and values of the community. Eight CLHW workers, with four alternate workers, were identified during the first year (Two CLHW's were dropped early in the project with the closure of one of the selected communities). The ages ranged between 25-75 years of age with 90% of them being unemployed. They all had a high school education or equivalency however, none of them were as proficient in handling the questionnaire as we had hoped. For the purposes of the questionnaire administration, we provided Morehouse School of Medicine graduate students. CLHW's facilitated the interview by making the initial contact with the community resident.

To a large extent, these workers, already familiar with the community ecology, solicited support for the project from community leaders ("gatekeepers"). With the support of these leaders, CLHW's frequently attended community-gathering places to build trust relationships and to establish credibility for the study. They translated and promoted the Breast Health Education Study (BHES), and generated widespread community support for the program.

Each CLHW took responsibility for the project and seemed to gain satisfaction in being part of the study. They developed a comfort level with working with individuals from higher income and education levels than what they had attained. The BHES staffers gained knowledge of the community ecology through the close working relationship developed with these women. A key person in the success of the CLHW concept was our Community Supervisor. She went into the communities with the CLHW, supervised their work related to the questionnaire administration, and monitored the process to ensure successful completion (see copy of recent publication included in the document).

Result of the Community Survey:

The original proposal stated that we would have a case comparison study using 200 subjects in the intervention group and 200 subjects in the control group. The women in the study would range in age from 35-79 years of age and would be assessed pre and post-test, to identify the knowledge, attitudes and practices of the participants regarding breast health. Power analysis included a 20-30 percent improvement, one sided testing at 0.05 level, with 80% power. The minimum number of participants needed for each group was 75.

With each progress report, during the course of this study, we've reported the challenges we have encountered in gathering data and conducting the project in such a way as to secure the power needed to show significance. This past no-cost-extension year was spent primarily trying to contact the pretest participants for completion of the post-test survey. The dismantling or reorganization of the low-rise communities in this study made this task difficult. As a result, the study was not as successful as we had anticipated.

As stated in previous reports, the initial or community survey tested for the general cancer prevention and control knowledge of the community. It included questions about other cancer screening practices and included men in the survey. For the purposes of our report related to breast cancer prevention men, were factored out leaving a sample size of 162 women.

Table 1 reveals the sociodemographic characteristics of African-American women age 20 years and older. A total of 162 women completed the community survey. Of this number 46.3% were forty years of age or older. The majority of the women (82%) were not married at the time of the study. Most of them (54%) had not completed a 12th grade education, were retired (29%), or unemployed (55%). Forty-three percent of the respondents made less than \$5000 annually. Of note is the fact that 54% received Medicaid and 12% received Medicare benefits.

The overall cancer prevention knowledge base for these women was low (see table 2). Less than one third of the women surveyed knew that age and obesity are risk factors for breast cancer. Other areas that showed a low level of knowledge included a lack of knowledge of an association between late parity, late menopause, and early menarche with breast cancer. However, about half of the women knew that having a positive family history for breast cancer is a risk factor.

Most of the women questioned had some knowledge of/or could name the breast cancer screening tests to be the breast self exam (BSE), the clinical breast exam (CBE), and mammography. Almost 90% agreed that breast cancer could be found early, and 93% agreed that finding and treating breast cancer early could save a woman's life. Of note, only 25% of those surveyed felt that they were personally at risk for getting breast cancer.

Table 3 shows the breast cancer screening practices of African-American women 20 years of age and older. Seventy three percent of the women in the survey had ever performed a breast self-

examination, but of these 68% did not follow the recommendations for doing the BSE on a monthly basis. Eighty-eight percent of the respondents had ever had a clinical breast exam (CBE) and 53% had ever had a .

TABLE 1. Sociodemographic Characteristics of African-American Women 20 years of Age and Older.
(N=162)

Variable	Percentage
<u>Age</u>	
20-29	25.3
30-39	19.1
40-49	9.3
50-59	10.5
60-69	12.3
70-79	11.1
80-89	9.9
90-99	2.5
<u>Marital Status</u>	
Not Married	81.5
Married	17.9
Don't Know/Refused Response	0.6
<u>Education</u>	
Less Than High School	53.7
High School	32.1
More Than High School	14.2
<u>Employment Status</u>	
Employed	11.1
Retired	29.6
Unemployed	54.9
Don't Know/Refused Response	4.3
<u>Income</u>	
<5,000	43.8
5,001-10,000	35.8
10,001-15,000	4.3
15,001-25,000	2.5
>25,000	0.6
Don't Know/Refused Response	13.0
<u>History of Breast Cancer</u>	
Yes	2.5
No	96.3
Don't Know	0.6
<u>Insurance Status</u>	
Private	6.2
Medicaid	53.7
Medicare	12.3
Other	17.3
None	9.9
Don't Know/Refused Response	0.6

TABLE 2. Breast Cancer Knowledge, Attitudes, and Beliefs in African-American Women 20 Years of Age and Older (N=162)

Variable	Percentage
<u>Know Breast Cancer Risk Factors</u>	
Age ≥ 40 Years Old (Yes)	32.1
Positive Family History (Yes)	58.6
Obesity (Yes)	27.2
First Child After 30 Years Old (Yes)	16.0
Menopause After 50 Years Old (Yes)	23.5
Menarche Before 12 Years Old (Yes)	9.9
High Fat Diet (Yes)	38.3
<u>Can Name Breast Cancer Screening Tests</u>	
Breast Self-Examination	87.7
Clinical Breast Examination	93.2
Mammography	86.4
<u>Breast Cancer Attitudes and Beliefs</u>	
There is no reason for a woman to get a mammogram if she is not sick (Yes)	8.6
Breast cancer can be found early (Yes)	88.9
Finding and treating breast cancer can save a woman's life (Yes)	92.6
Respondent feels susceptible to getting breast cancer	24.7

TABLE 3. Breast Cancer Screening Practices of African-American Women 20 Years of Age and Older (N=162)

Variable	Percentage
<u>Has Ever Performed Breast Self Examination</u>	
Yes	72.8
No	24.7
Don't Know/Refused Response	2.5
<u>Breast Self Examination Frequency (N=110)</u>	
Monthly	32.2
Other	67.8
<u>Has Ever Received a CBE</u>	
Yes	88.3
No	7.4
Don't Know/Refused Response	4.3
<u>Has Ever Had A Mammogram</u>	
Yes	53.1
No	43.8
Don't Know/Refused Response	3.1

Results of the Post-Test Only Comparison Group Study:

In review of the data compiled, it was determined that many of the original survey participants did not attend the workshops. However, there were a lot of people from the community who didn't do the original survey but did attend the workshop intervention. Therefore, we have no pretest data on them. A total of 56 cases (women who participated in the Breast Health Education Workshop) completed a post-test survey. A total of 64 comparisons (women who *did not* attend the workshop) completed the post-test survey. The data from these surveys is included in this report.

By using the post-test only comparison group study design we will be able to measure the effect of our intervention on the cases by comparing them with the comparison group. We won't, however, be able to determine the extent of change that may have occurred within the case group.

The demographics of this sample show that the majority of the women who participated in the intervention were 70-79 years of age (39%) while twenty-eight percent of the comparison group were age 20-29, and this difference was statistically significant. More cases than comparisons had less than a high school education ($p < 0.001$) and more of the comparison group was currently employed ($p\text{-value} = 0.001$). This change is probably reflective of the comparison group being younger than the cases. The cases were more likely to have Medicare or some other insurance while the comparison group members were more likely to have Medicaid ($p = 0.003$). There is no difference between cases and comparisons when looking at marital status, income level and the history of breast cancer (Table 4).

As in the community survey, the overall knowledge base was low for risk factors. Table 5 shows the knowledge, attitudes and beliefs surrounding breast cancer prevention and control. Cases and comparisons showed no difference women's knowledge of age, family history, late parity, late menopause, early menarche and high fat diets as risk factors for breast cancer. The data shows significance when comparing cases and comparisons in the knowledge that obesity is a risk factor ($p\text{-value} 0.03$) and in their knowledge that age 40 and older is a risk factor ($p\text{-value} 0.20$). For women 50 and older more of the cases than controls knew that they should get a breast exam every year or every two years ($p 0.05$).

There is no difference between cases and comparisons in knowing the screening tests used to detect breast cancer - breast self-examination (BSE), clinical breast examination (CBE), and mammography. The overall knowledge of the screening tests was high for both groups. Also, there was no difference between cases and controls in their knowledge of the frequency by which women should get a mammogram (Table 5).

Table 4. Sociodemographic Characteristics of Study Participants by Case-Control Status

Variable	Cases ¹ (n=56) %	Comparisons (n=64) %	p-value
<u>Age (yrs)</u>			
20-29	1.8	28.1	< 0.001
30-39	3.6	20.3	
40-49	5.4	7.8	
50-59	12.5	12.5	
60-69	14.3	14.1	
70-79	39.3	7.8	
80-89	14.3	7.8	
90-99	8.9	1.6	
<u>Marital Status</u>			
Not Married	82.1	78.1	0.58
Married	17.9	21.9	
<u>Education</u>			
Less than H.S.	83.9	50.0	< 0.001
H.S.	7.1	28.1	
More than H.S.	8.9	20.3	
Don't Know/Refused Response	...	1.6	
<u>Employment Status</u>			
Employed	3.6	10.9	0.001
Retired	67.9	32.8	
Unemployed	28.6	51.6	
Don't Know/Refused Response	...	4.7	
<u>Income</u>			
< 5000	48.2	53.1	0.48
5,001-10,000	35.7	37.5	
10,001-15,000	5.4	1.6	
15,001-25,000	1.8	...	
Don't Know/Refused Response	8.9	7.8	
<u>History of Breast Cancer</u>			
Yes	7.1	...	0.09
No	92.9	100.0	

¹ Cases are women who participated in the Breast Health Education Workshop, comparisons are women who did not.

Table 4. Sociodemographic Characteristics of Study Participants by Case-Control Status (cont.)

Variable	Cases¹ (n=56) %	Comparisons (n=64) %	p-value
<u>Insurance Status</u>			
Private	7.1	6.3	0.003
Medicaid	19.6	40.6	
Medicare	28.6	25.0	
Other	39.3	7.8	
None	5.4	15.6	
Don't know/Refuse Response	...	4.7	

¹ Cases are women who participated in the Breast Health Education Workshop, comparisons are women who did not.

Table 5. Knowledge, Attitudes, and Beliefs Surrounding Breast Cancer Prevention and Control, by Case-Control Status

Variable	Cases (n=56) %	Comparisons (n=64) %	p-value
<u>Know Breast Cancer Risk Factors</u>			
Age ≥ 40 years old	37.5	26.6	0.20
Positive Family History	39.3	50.0	0.24
First Child after 30 years old	21.4	17.2	0.56
Menopause after 50 years old	25.0	21.9	0.69
Menarche before 12 years old	12.5	10.9	0.79
Obesity	32.1	15.6	0.03
High Fat Diet	53.6	42.2	0.21
<u>Can Name Breast Cancer Screening Tests</u>			
Breast Self Examination	82.1	82.8	0.92
Clinical Breast Examination	92.9	93.8	0.86
Mammography	82.1	92.2	0.10
<u>All Women (n=120)</u>			
Report that breast self-exam should be perfoemed:			
Monthly	44.6	42.2	0.10
Other	41.1	21.9	
Don't know/Refuse Response	14.3	35.9	
<u>Women 50 years and older (n=78)¹</u>	(n=50)	(n=28)	
Report that a clinical breast exam should be obtained by a woman her age:			
Yearly	52.0	32.1	0.05
Every 2 years	4.0	3.6	
Other	34.0	28.6	
Don't know/Refused Response	10.0	35.7	
<u>Women 50 years and older (n=78)</u>	(n=50)	(n=28)	
Report that a mammogram should be obtained by a woman her age			
Yearly	46.0	35.7	0.50
Every 2 years	4.0	3.6	
Other	30.0	25.0	
Don't know/Refused Response	20.0	35.7	

¹ Analysis not shown for women 40-49 due to small sample size (n=8).

Table 5. Knowledge, Attitudes, and Beliefs Surrounding Breast Cancer Prevention and Control, by Case-Control Status (continued)

Variable	Cases (n=56) %	Comparisons (n=64) %	p-value
<u>Breast Cancer Attitudes & Beliefs</u>			
There is no reason for a women to get a mammogram if she is not sick	8.9	10.9	0.71
Breast Cancer can be found early	87.5	95.3	0.16
Finding and Treading breast cancer early can save a women's life	91.1	95.3	0.55
Respondent feels susceptible to getting breast cancer	39.2	35.9	0.70

Table 6. Prior Breast Cancer Screening Practices by Case-Control Status

Variable	Cases (n=56) %	Comparisons (n=64) %	p-value
Has ever performed breast self exam			
Yes	82.1	84.4	0.74
No	17.9	12.5	
Don't know/Refuse response	...	3.1	
Breast self-exam (frequency)¹			
Monthly	28.3	40.7	0.19
Other	71.7	59.3	
Has ever obtained a clinical breast exam			
Yes	96.4	92.2	0.53
No	3.6	6.3	
Don't know/Refused response	...	1.6	
Has ever obtained a mammogram			
Yes	85.7	53.1	< 0.001
No	7.1	43.8	
Don't know/Refuse response	7.1	3.1	

¹ Breast self-exam frequency for women who reported "yes" to ever performing a breast self-exam.

Table 7. Myths and Other Misconceptions Surrounding Breast Cancer Prevention & Control, by Case Comparison Status

Variable	Cases (n=56) %	Comparisons (n=64) %	p-value
Breast Cancer is associated with bumping or bruising the breast	71.4	50.0	0.02
Breast cancer is associated with stress	33.9	34.4	0.96
Breast cancer is associated with smoking	57.1	71.9	0.09
Named pap smear as a screening test for breast cancer	55.4	35.9	0.03
Named chest x-ray as a screening test for breast cancer	75.0	70.3	0.57

There was no difference in the attitudes and beliefs of cases and comparisons in response to “finding and treating breast cancer early can save a woman’s life”; that there is no reason to get a mammogram if a woman is not sick; and that breast cancer can be found early. The cases and comparisons were equally as likely to feel that there was no reason for a woman to get a mammogram or feel susceptible for getting breast cancer (See table 5).

In Table 6 there is no difference between the screening practices of the cases and the comparison groups in doing the BSE monthly. Of interest, only 28 % of the cases knew that BSE should be done once a month with 72% of the respondents indicating *other* for that response. Eighty-six percent of the cases and 53% of the comparison group had ever had a mammogram (p-value <0.001)

In review of Table 7, over 70% of cases and comparisons named the chest xray as a screening test for breast cancer. However, this was not statistically significant between the two groups. Fifty five percent of the cases and 36% of the controls named the pap smear as a screening test for breast cancer (p-value 0.03). More cases than comparisons believe that breast cancer is associated with bumping or bruising the breast was high in both groups (cases 71.4%, comparisons 50%, p=0.03).

Discussion : The results of the community survey and the post-test only case comparison study reflects some of the problems pertaining to the collection of data. The women surveyed ranged in age from 20 –99 years of age. They had less than a high school level of education, were impoverished and largely depended on publicly funded sources of healthcare insurance. The overall knowledge of breast cancer risk factors was low however, the case group showed more knowledge in those areas of significance than the comparison group (age, obesity, and the frequency for getting the clinical breast exam. Both groups showed a high level of knowledge about the mammogram as a screening test for breast cancer.

Myths and misconceptions were addressed in the intervention in an attempt to dispel these concepts. However, the myth that breast cancer is caused by bumping or bruising the breast was significant. Of interest was the belief by the respondents that the pap smear is a screening test for breast cancer (p-value 0.03).

Some of the differences could be due to the workshop intervention. However, the disparity in the age range of the case and comparison group has probably caused an age bias. Multivariate analysis that stratifies for age is needed to accurately analyze this data.

Results of the Infodrama Evaluation:

Five Infodrama presentations were conducted at conferences, seminars and other programs during this study. A total of 76 healthcare providers (including 40 physicians and 36 nurses) participated in the Infodrama from May 1995 to April 1997. Post-test instruments were mailed out to all participants for completion beginning six weeks post intervention. Twenty- eight of the 40 physicians who participated in the Infodrama completed post-test surveys after three mailings and one telephone reminder encouraging them to complete the instrument. The response rate for nurses was even lower (15 returned questionnaires). Due to the low response rate of the nurses only the physician data is reported. The following analysis looks at the physician group only.

The physician group of participants consisted of 75% male physicians with 25% females. The post-test surveys were completed primarily by the women physicians (p-value 0.03). Most participants were African-American (75% pre and post-test).

Ten percent of the participants were Family Physicians with 52.5% of the attendees describing themselves as Internists. However there was a post-test response rate of 71% (p-value <0.001) amongst the Family Physicians with only 17.9% of the Internists completing the post-test survey instrument. Most of the participants had been in practice for less than 5 years (not statistically significant).

Table 2. looks at the *Knowledge, Attitudes and Beliefs Concerning Breast Cancer Prevention and Control by Pretest-Posttest Status*. There was an increase in the percentage of physicians who thought that the following variables were important or somewhat important in breast cancer prevention:

- cultural beliefs (72% pre, 89% post);
- not having a physician tell the patient to have a clinical breast exam and mammogram (77% pretest, 92% post-test);
- transportation (57.5% pre, 78.6% post); and
- discomfort associated with getting a mammogram (65% pre, 89% post).

Although there was an increase in these variables they did not reach significance.

There is no difference between pretest and post test results of physicians knowing the age that women are most likely to get breast cancer. Of interest, overall less than half of the physicians knew that women over 50 are most likely to get breast cancer. When asked questions concerning the physicians ability to educate/counsel patients on breast cancer prevention there was disagreement in the statement *"I don't have time to educate patients"*. However, in the strongly

agree category for this question, there was an increase from 2.5% (pre-test) to 14.3%(post-test). For the statement *"After I counsel a patient, I don't think they comply with my recommendations"* there was a decrease from 5% to 0% (post) in the strongly agree category.

In evaluating the change in screening practices of physicians pre and post-test there was a significant increase in the percentage of post-test physicians recommending the clinical breast exam for patients (p-value 0.04). We also see a trend towards an increase in the percentage of those recommending the breast self-examination however this was not of significance.

Table 1. Sociodemographic Characteristics of Physician Study Participants, by Pretest-Posttest Status

Variable	Pretest (n=40) %	Posttest (n=28) %	p-value
<u>Gender</u>			
Female	25.0	50.0	0.03
Male	75.0	50.0	
<u>Race</u>			
African-American	75.0	75.0	0.60
Asian/Pacific Islander	7.5	10.7	
White-American	2.5	7.1	
Other	15.0	7.1	
<u>Specialty</u>			
Family Practice	10.0	71.4	<0.001
Internal Medicine	52.5	17.9	
Obstetrics/Gynecology	7.5	3.6	
Pediatrics	5.0	7.1	
Surgery	2.5	...	
Other	12.5	...	
<u>Years in Practice</u>			
≤ 5 years	45.0	32.1	0.70
6 - 10 years	12.5	21.4	
11 - 15 years	10.0	17.9	
16 - 20 years	10.0	10.7	
> 20 years	17.5	17.9	
No Response	5.0	...	

Table 2. Physician Knowledge, Attitudes, and Beliefs Concerning Breast Cancer Prevention and Control, by Pretest-Posttest Status

Variable	Pretest (n=40) %	Posttest (n=28) %	p-value
<u>At what age do you think women are most likely to get breast cancer?</u>			
40 - 50 years of age	52.5	60.7	0.64
> 50 years of age	45.0	39.3	
There is no age difference in the likelihood of getting breast cancer	2.5	...	
<u>Are the following very important, somewhat important, or not very important in keeping women from getting clinical breast exams and mammograms?</u>			
Fear			
very important	50.0	39.3	0.65
somewhat important	37.5	42.9	
not very important	7.5	17.9	
no response	5.0	...	
Not going to the doctor unless they have problems			
very important	62.5	53.6	0.19
somewhat important	25.0	42.9	
not very important	7.5	3.6	
no response	5.0	...	
Cultural beliefs			
very important	27.5	50.0	0.10
somewhat important	45.0	39.3	
not very important	20.0	10.7	
no response	7.5	...	
Not knowing that they are at risk of getting breast cancer			
very important	35.0	35.7	0.77
somewhat important	32.5	39.3	
not very important	25.0	25.0	
no response	7.5	...	
Cost			
very important	35.0	42.9	0.79
somewhat important	42.5	35.7	
not very important	14.1	21.4	
no response	7.5	...	

Table 2. Physician Knowledge, Attitudes, and Beliefs Concerning Breast Cancer Prevention and Control, by Pretest-Posttest Status (cont.)

Variable	Pretest (n=40) %	Posttest (n=28) %	p-value
<u>Are the following very important, somewhat important, or not very important in keeping women from getting clinical breast exams and mammograms?</u>			
Not being told by a doctor to have a clinical breast exam or mammogram			
very important	35.0	32.1	0.17
somewhat important	42.5	60.7	
not very important	17.5	7.1	
no response	5.0	...	
Embarrassment			
very important	25.0	28.6	0.40
somewhat important	42.5	53.6	
not very important	25.0	17.9	
no response	7.5	...	
They don't think they need one			
very important	37.5	28.6	0.67
somewhat important	47.5	50.0	
not very important	10.0	21.4	
no response	5.0	...	
Transportation problems			
very important	7.5	14.3	0.17
somewhat important	50.0	64.3	
not very important	35.0	21.4	
no response	7.5	...	
Discomfort associated with getting a mammogram			
very important	20.0	32.1	0.07
somewhat important	45.0	57.1	
not very important	27.5	10.7	
no response	7.5	...	
Lack of insurance			
very important	47.5	64.3	0.30
somewhat important	35.0	28.6	
not very important	10.0	7.1	
no response	7.5	...	
Lack of time			
very important	20.0	32.1	0.52
somewhat important	47.5	39.3	
not very important	25.0	28.6	
no response	7.5	...	

Table 2. Physician Knowledge, Attitudes, and Beliefs Concerning Breast Cancer Prevention and Control, by Pretest-Posttest Status (cont.)

Variable	Pretest (n=40) %	Posttest (n=28) %	p-value
<u>The following statements are about your feelings concerning breast cancer prevention. Do you strongly agree, agree, disagree, or strongly disagree?</u>			
I have sufficient knowledge to counsel patients.			
strongly agree	40.0	50.0	0.66
agree	45.0	42.9	
disagree	7.5	...	
strongly disagree	5.0	7.1	
no response	2.5	...	
I don't have enough time to educate patients.			
strongly agree	2.5	14.3	0.13
agree	25.0	10.7	
disagree	30.0	42.9	
strongly disagree	37.5	32.1	
no response	5.0	...	
When counseling patients, I am concerned that I may give incorrect recommendations.			
strongly agree	2.5	7.1	0.63
agree	12.5	10.7	
disagree	32.5	42.9	
strongly disagree	50.0	39.3	
no response	2.5	...	
After I counsel a patient, I don't think they comply with my recommendations.			
strongly agree	5.0	...	0.10
agree	35.0	42.9	
disagree	50.0	32.1	
strongly disagree	7.5	25.0	
no response	2.5	...	
I don't think the women who need breast cancer education and screening are the ones I see.			
strongly agree	12.5	25.9	0.63
agree	22.5	25.9	
disagree	30.0	29.6	
strongly disagree	27.5	18.5	
no response	7.5	...	

Table 3. Breast Health Patient Education, Screening Practices, and Referral Patterns by Physicians, by Pretest-Posttest Status

Variable	Pretest (n=40) %	Posttest (n=28) %	p-value
<u>On average, how much time do you spend each week educating your patients about breast health?</u>			
0	10.0	10.7	0.67
1 -3 hours	55.0	50.0	
4 - 6 hours	15.0	28.6	
7 - 9 hours	2.5	...	
10 hours or more	7.5	3.6	
No response	10.0	7.1	
<u>What breast cancer screening tests and procedures do you usually recommend for patients?</u>			
Breast self-examination (yes)	77.5	92.8	0.12
Clinical breast-examination (yes)	55.0	78.6	0.04
Mammography (yes)	67.5	64.3	0.78

Discussion: As mentioned earlier, several problems were encountered in getting the Infodrama to our constituency. We fell short of the intended number 150 physicians to be trained on breast cancer prevention and control during the grant period. This results in a decrease in the power of our tabulations and affects the assumptions that can be made. However, it seems that from this data we can assume that the primary care physicians most likely to participate in this type of continuing medical education activity would be Family Physicians; physicians in practice for less than five years and physicians who are female. This is probably a reflection of those physicians, other than specialists in OG/GYN, who provide health care for women. There seems to be a trend towards an increase in the percentage of physicians who understand the importance of the physician advocating that a woman gets breast cancer screening. The fact that half of the post test participants are women may bias the data due perhaps to their vested interest in this particular screening tool.

There also seems to be an increase in the level of understanding obtained by the physicians in the socio-economic and cultural factors associated with the patients' compliance with a recommendation after the intervention however, this was not of significance. These factors include the level of discomfort thought to be part of the experience during the mammogram, the lack of transportation and the myths or misconceptions that the patient has based on cultural beliefs/experiences.

The physicians surveyed felt confident in their ability to counsel patients. Consequently, we saw no difference in the number of hours they spent counseling the patient's post Infodrama intervention.

Recommendations:

Community based research is an important mechanism for obtaining information about certain populations. It is, however, probably the most difficult type of research to do. The problems we encountered in this study, though unusual, given the fact that the Housing Authority partnered with us to identify and select the communities when they knew that these communities would be changed or dissolved, they are common when dealing with poor and under served people. The concept of involving the community in the project, hiring and training community residents to work in the project along with the researchers is a concept that should continue to be promoted. We could not have been able to get the data we were able to obtain without the help and support of the Community Lay Health Worker. Of even more importance is the fact that these women remain in the community as a resource for their neighbors.

The Infodrama presentation received positive comments from the participants (anecdotal) in conversations with the participant's post intervention. They expressed their hesitancy in attending

the workshop initially because the term "Infodrama" was in the title and they did not want to be in an interactive session. We learned, late in the study, to list the intervention as a breast cancer prevention workshop to avoid selection bias on the part of the physician.

Additionally, for the conference planners we contacted, quite a bit of documentation explaining the conference and the learning objectives was required before they understood that the conference was a training and not just entertainment. This is crucial in order to have the presentation scheduled during the high attendance portion of the conference.

References

1. American Cancer Society, Cancer Facts and figures - 1995
2. Ries, LAG, Miller, BA, Henkey, BF, Kosary, CL, Hargraves, A, Edwards (eds).
Seer Cancer Statistics Review, 1973 - 1991: Tables & Graphs, National Cancer
Institute. NIH Pub. No. 94-2789. Bethesda, MD, 1994
3. Coates, RJ, Clark, WS, Eley, JW, et. al. Race, nutritional Status, and Survival From
Breast Cancer. J. Natl Cancer Inst. 1990;82:1684-1692.
4. Hunter, CP, Redmond, CK, Chen, VW, et. al. Breast Cancer: Factors Associated with stage
at Diagnosis in Black Women and White Women. J. Natl. Cancer Inst. 1990;85:1129-
1137
5. Elledge, RM, Clark, GM, Chamness, GC, et. al. Tumor Biologic Factors and Breast Cancer
Prognosis Among White, Hispanic, and Black Women in the United States. J. Natl.
Cancer Inst. 1994;86:705-712
6. Eley, JW, Hill, HA, Chen, VW, et al. Racial Difference in Survival Rates From Breast Cancer
Results of the National Cancer Institute Black/ White Cancer Survival Study. JAMA.
1994;272:947-54
7. Moormeier, J. Breast Cancer in Black Women. Ann Intern Med. 1996;124:897-905
8. Centers for Disease Control and Prevention. Trends in Screening Mammograms for Women
50 Years of Age and Older - Behavior Risk Factor Surveillance System, 1987. MMWR.
1989;38:137-140.
9. Breen, B, Kenler, L. Changes in the Use of Screening Mammography: Evidence from the
1987 and 1990 National Health Interview Surveys. Amer. J. Pub. Health 1994;84:62-67
10. Seer 1987-1991
11. Burack, RC, Gitmotty, PA, Stengle, W, et al. Patterns of Use of Mammography Among
Inner-City Detroit Women: Contrast Between Health Department, HMO, and Private
Hospital Med. Care. 1993;31:322-334
12. Fox, SA, Stein, JA. The Effect of Physician-Patient Communication on Mammography
Utilization by Different Ethnic Groups. Med Care. 1991;29:1065-1082

13. Rimer, BK, Trock, B, Engstrom, PF, et al. Why Do Some Women Get Regular Mammograms. *Am. J. Prev. Med.* 1991;7:69-74
14. Mickley, RM, Durski, J, Worden, JK, et. al. Breast Cancer Screening and Associated Factors for Low-Income African-American Women. *Preventive Medicine.* 1995;24:467-476
15. Smith, RA, Haynes, S. Barriers to Screening for Breast Cancer. *Cancer* 1992;69:1968-1978
16. Roetzheim, RG, Van Durme, DJ, Brownlee, HJ et al. Barriers to Screening Among Participants of Media-Promoted Breast Cancer Screening Project. *Cancer Detection and Prevention* 1993;
17. Healthy People 2000. National Health Promotion and Disease Prevention Objects. DHHS Publication (PHS) 91-50212. U.S. Government Printing Office, Washington, DC.
18. Braithwaite, RL, Lythcott, N. Community Empowerment as a Strategy for health Promotion for Black and Other Minority Populations. *JAMA*, Jan 13, 1989; vol.261, No.2.

Bibliography

Publications/Presentations/Manuscripts Developed as a Result of this Grant

Hill, CV. "An Exploratory Study: Demographic and Social Barriers To Breast Cancer Screening Among Low Income Black Women In Atlanta, Georgia." Thesis manuscript. Master of Public Health Program, Morehouse School of Medicine, July 1997.

Taylor, BD, Sheats J, Murphy, F, et. al., Training Community Health Volunteers for Breast Health Education and Disease Prevention. *American Journal of Health Promotion*. Accepted subject to revision.

Presentations:

Taylor, BD, et. al., Breast Cancer screening Practices Amongst Primary Care Practitioners. Focus Group with Family Practice Residents, Morehouse School of Medicine, January , 1995

Taylor, BD, et. al. *Nightmare*, presented at the noon conference for Internal Medicine residents at Grady Memorial Hospital, Atlanta, Georgia, April 1995.

Taylor, BD, et.al. *Nightmare*, presented at the Annual Meeting of the Georgia Medical Association, June 19, 1996

Taylor, BD, et. al. *Nightmare*, presented at the Georgia Academy of Family Physician's Meeting, October, 1996.

Taylor, BD, "Utilizing the Community Lay Health worker for Breast Health Education", poster presentation presented at the American Public Health Association Meeting, 1996, Community Health Planning and Policy Development, Women's Health Section, New York, November 17-21, 1996.

Taylor, BD, et. al. The Infodrama as an Effective Tool in Medical Education, presented at APHA, Women's Health Section, New York, November 17-21, 1996.

Taylor, BD, "Breast Cancer Prevention, and Control", presented at Advances in Primary Care: Practical Approaches to the African - American Patient, April 26, 1997, Atlanta, Georgia.

Taylor, Beverly D.

DAMD17-94-J-4134

Community Presentation of the Breast Health Education Workshops:

<i>Community</i>	<i>Date</i>
Graves Annex	Nov. 6, 1996
Martin Luther King, Jr.	January 21, 1997
John O. Chiles	April 24, 1997
Cosby Spears	May 6, 1997
Villa Monte	July 2, 1997
Antone Graves	July 8, 1997

Participants in the Breast Health Education Project who received funds from grant #DAMD17-94-J-4134 from June 30, 1994 through July 31, 1997.

Charlee Lambert	Consultant
Frederick Murphy	Consultant
Mable Densler	Outreach Coordinator
Mattie Kelly	Community Health Worker
Annie R. Cofer	Community Health Worker
Robin Hawkins	Community Health Worker
Eugenia Dickerson	Community Health Worker
Catherine Epps	Community Health Worker
Eva B. Davis	Community Health Worker
Joyce Sheats	Project Director
Bridget Toodle	Administrative Secretary
Carl Hill	Student Research Assistant
Sherri Simpson	Student Research Assistant

Kenya Beverly	Student Research Assistant
Germaine Cummings	Student Research Assistant
Joyce Ellis	Community Health Worker Trainee
Helen Heath	Community Health Worker Trainee
Carol Dupree	Community Health Worker Trainee

TRANSLATING BREAST HEALTH: A ROLE FOR COMMUNITY LAY HEALTH WORKERS IN THE 21TH CENTURY

Beverly D. Taylor, MD
Frederick G. Murphy, MSHyg., MPIA
Joyce Q. Sheats, RN
Mable W. Densler, RN
Sherry R. Crump, MD, MPH

Abstract: In recent decades the health care system in the US has attempted to improve the quality of its preventive and primary care services. The inclusion of a non-traditional worker force, such as community lay health workers, is a relevant and positive addition in the pursuit of this most worthwhile public health goal. The Community Lay Health Worker (CLHW) can increase access to care and facilitate appropriate use of health resources by: providing outreach and cultural linkages between communities and health care delivery systems; reducing costs of providing health education, screening, detection and basic emergency care; and improving the quality of care, continuity of care, patient-provider communication and consumer protection. Information sharing, program support, program evaluation, and continuing education are needed to expand the use of community lay health workers and to better integrate them into the health care delivery system (Wimer, Seifer, Finocchio, Leslie, & O'Neil, 1995). [Am J Health Studies 1998; 14(3): 137-142]

PROJECT OVERVIEW

In 1994, the Morehouse School of Medicine (MSM) began the implementation of a Breast Health Education Study (BHES) that focused on two specific target groups: (1) minority, medically under-served women in metropolitan communities and, (2) primary care physicians and other health care providers who care for these medically under-served. The study determined and validated the efficacy of community-based educational program initiatives in promoting breast health, by educating and motivating women to seek mammograms and perform breast self-examinations on a regular basis. Breast health education, targeting under-

served women in low-income communities, was conducted through collaboration between Community Lay Health Workers (CLHWs) and the Southeastern Region of the National Black Leadership Initiative On Cancer (NBLIC).

The over-arching purpose of the breast health education project was to address three goals set forth in Healthy People 2000 Objectives for the Nation. These include: 1) to increase the span of healthy life, 2) to reduce health disparities, 3) and to establish access to preventive services for all Americans (HHS, US Public Health Service, 1990). Through the utilization of culturally sensitive, yet innovative intervention approaches,

Beverly D. Taylor, MD, is an Associate Professor, Sherry R. Crump, MD, MPH is an Assistant Professor, and Mable W. Densler, RN, is a Consultant in the Department of Community Health and Preventive Medicine at the Morehouse School of Medicine. Joyce Q. Sheats, RN, MPH, is the Project Director of NBLIC National Office in Morehouse School of Medicine. Frederick G. Murphy, MSHyg, MPIA, is the Director in the Southeastern Primary Care Consortium, Inc. Address correspondence to: Frederick G. Murphy, MSPH, MPIA, Southeastern Primary Care Consortium, Inc., 1039 Ridge Ave., S.W, Atlanta, GA 30315.

the BHES sought to increase rates at which low-income inner city women obtain clinical breast examinations and mammograms.

A strong correlation has also been drawn between lower socioeconomic status and shortened breast cancer survival (Sung, Coates, Williams, Liff, Greenberg, Avery & Blumenthal, 1992). Current statistics reveal that approximately 33% of all African-Americans are poor. (Cancer Facts and Figures). Freeman has suggested that at least half of the difference in cancer survival among disadvantaged people is due to late diagnosis and lack of adequate secondary prevention. While the incidence of breast cancer is higher in white women, mortality rates from breast cancer are higher in African American women (Freeman, Wasfie, 1989). This higher mortality rate is thought to be attributed to: 1) socioeconomic status, 2) hormonal issues and, 3) the more advanced stage of disease at the time of diagnosis (Baquet, Ringer & Young, 1986; Farley & Flannery, 1989).

The National Health Interview Study (NHIS) of trends in use of preventive health care by U.S. women found that the percentage of women having a recent breast exam between 1973 and 1985 increased substantially for all women age 60 to 79. The increases were greater for black women (23%) than for white women (10%) in this age group. The poor were less likely than others to have preventive cancer care in this study. Women eligible for mammography reported that the most important reasons for not receiving a recent mammogram were that they "did not know about it" or that their "doctor did not recommend it." Physicians reported a number of barriers to their recommendation that patients submit to mammograms examination including: cost, belief that the examination is unnecessary, and concerns about the risk of radiation exposure. Cost has also been reported by many low-income women to be a key inhibiting factor to mammography utilization. In addition, low education, advancing age, and the lack of a usual source of health care have been associated with lower mammography utilization rates (Burack & Liang, 1989; Thompson, Kessler, Boss, 1989). In addition to higher mortality and lower survival rates, socio-economically disadvan-

tagged African-American women face other unique problems. Allen and Britt noted that black women are disadvantaged members of the work force, and that on average, they hold lower status jobs, earn less, and work longer than other major social groups (Allen, Britt, 1983; Giblin, 1989; Indian Health Service, 1991).

Current national and state health care reform efforts have resulted in many proposals for restructuring the delivery and financing of care. These efforts to rationalize and streamline the health care system have uncovered the need for a health care work force armed with the knowledge, skills, and attitudes to successfully implement change (Kaiser Commission on the Future of Medicaid, 1994; O'Neil, 1993). This will require a cadre of providers able to overcome cultural barriers and to assimilate a variety of languages, and health beliefs into their practices. To date, health work force reform initiatives have largely focused on the training and distribution of primary care providers. An important but largely overlooked member of the health care work force is the community lay health worker and volunteer (Wimer, Seifer, Finocchio, Leslie, O'Neil, 1995; Council on Graduate Medical Education, 1994).

BHES.COMMUNITY APPROACH

There is no single accepted definition of a community lay health worker, or for any other title commonly applied to lay health providers. In the MSM BHES, community lay health workers were defined as: community members who lived almost exclusively in low income community settings, and who were trained to serve as translators between community participants, health care providers and project administrators. Their primary role was to assist in helping to promote breast health information among group which have traditionally lacked access to adequate health messages and care. Black and White women alike are regularly exposed to health-related messages through the media and the work of public agencies and non-profit organizations. These commonly-used education methods and approaches, however, may not be the most culturally appropriate for minority populations. Culturally appropriate interventions

employing minority men and women models, using culturally appropriate vocabulary, and delivered by persons of the same background as the target audience may prove the most productive and translatable materials. The BHES showed this as the case during the course of its study. By helping project investigators and administrators identify community problems, develop innovative solutions, and translate those solutions into practice, community lay health workers played a key role in implementing culturally sensitive breast health education and screening programs.

The BHES replicated the concept of Community Lay Health Workers (CLHWs) and empowering community members. During the 1960's, the federal government supported community health worker programs as a vehicle for expanding access to health care for under-served communities. In some regions, federal and state grants to community-based health programs continue to support community health worker programs. Since 1968, the Indian Health Service has supported the only categorical health worker program (Indian Health Service, 1991).

The MSM BHES also utilized some of the lessons learned from a previous study completed at MSM in 1984. This study entitled: "Avoidable Mortality from Cancer in Black Populations" (AMCBP) also targeted black women in the inner city. Results of the study showed a 2.9% increase in pap smear screening, and a 34.5% increase in breast screening, through use of community workers (Sung, Coates, Williams, et al, 1993). Educational intervention methods used in the AMCBP study differed slightly from the BHES (in-home vs. community group); however, the target group profile was the same. The BHES study promoted a more culturally sensitive approach based on a philosophy of empowering low-income black women to help themselves and one another. For example, the Community Organization and Development Model (COD) developed through the MSM Health Promotion Resource Center in 1988 was used in the design of the study. This nationally-recognized model is based on the belief that health promotion efforts are likely to be more successful among minority and poor

populations when the communities at risk are empowered to identify their own problems. Community residents participate in the development of the intervention, and form decision-making coalition boards to make policy decisions and manage resources.

RECRUITMENT STRATEGIES AND TRAINING METHODS

The MSM BHES recruited community residents directly from low-income, inner-city communities. These individuals, who live in or near the intervention communities, were employed as CLHWs. To a considerable extent, these workers, already familiar with the community ecology, solicited support for the project from community leaders ("gatekeepers"). With the support of these leaders, CLHWs frequently attended community gathering places to build trust relationships and to establish credibility for the study. They translated and promoted the BHES, and generated widespread community support.

Specific steps were used in the CLHW recruitment process. First, appointments and orientation sessions were set up and conducted for community leaders from six low-income neighborhoods located in the southeast and southwest communities of inner-city Atlanta. These leaders held prominent positions within their communities such as the president of a tenant organization, and managers and social service directors. Second, leaders were given a complete overview of the BHES, and then asked if they would play an active role in recruiting community residents to participate as workers for the project. Third, leaders were asked to assist BHES staff in developing the interview protocol to be used in screening and selecting workers. A formal application form was developed and each interested resident was asked to complete an application form. Each applicant was required to have been a resident in the community for minimum of 2 years. Applications were reviewed by both community leaders and BHES staff, and a series of interviews was conducted to determine the final group of workers. Lastly, reading and writing proficiency tests were given to applicants to determine literacy levels. These residency requirements were

highlighted to assure that the workers selected were familiar with the socio-economic, ecological, environmental and political concerns and values of the community. A total of eight CLHW workers were recruited during the first year, to work with the project for its duration. In addition, four alternate workers were selected to serve as replacements or substitutes during the course of the study. The age range for all CLHWs selected was 25-75 years, with 90% unemployed.

A two week, intensive group training was conducted for all CLHWs and their alternates. Training instructors were MSM faculty and staff members with years of experience in working with community residents at the grassroots level. The development of training protocols for use in training workers required that all materials and exercises be culturally sensitive, and designed in a manner where translation and interpretation of information was substantially minimized.

Training protocols for the BHES included the following components: 1) Orientation to Project Mission and Design; 2) Overview of Breast Cancer Facts and Figures; 3) Code of Ethics, Duties and Responsibilities; 4) Design and Administration of Needs Health Assessments (Overview and Review) and 5) Role Play. During all training sessions group discussions were held to gather information from workers about community perceptions, issues, cultural values and traditions.

The type and length of training sessions were largely dependent upon the rate at which workers grasped breast health concepts. Although training for the workers lasted for a total of two weeks, follow-up training and discussion sessions were routinely conducted for ongoing modification of the intervention approach. The total recruitment selection and training process lasted for approximately six weeks.

CLHWs BREAST HEALTH EDUCATION PARTICIPATION

CLHWs were assigned to work directly under the supervision of a BHES staff person who was also a trained public health professional. Each staff person was responsible for organizing, scheduling and moni-

toring the day to day activities of each CLHW during the course of the study. CLHWs were directly accountable to staff, and were required to report on a pre-determined schedule. CLHWs worked each week with staff to organize and implement community data collection and education programs.

As community residents, neighbors, and family members, CLHWs also assisted BHES staff to translate breast health information, to make it more accessible within the community's language and value system. Working largely in under-served areas with high-risk populations, CLHWs facilitated health intervention access, while also helping relate basic breast health concepts related to primary or secondary prevention. For example, CLHWs were primary participants in the collection of behavioral and access data from over 200 community residents. These data were collected using an 84 question instrument modeled after the Behavioral Risk Factor Survey (BRFS) developed at the Center for Disease Control and Prevention. This direct involvement with residents helped to establish much needed relationships necessary to implement follow-up breast health workshops. A total of eight breast health education workshops were conducted, with CLHWs working along side BHES staff to schedule and conduct each workshop.

CONCLUSION

Although no single community health worker model is applicable to all communities and circumstances, international and domestic studies have identified common characteristics of successful programs. In the context of breast health, success is usually measured by completion of program objectives, program sustainability, impact on health care access, cost, and quality (Walt, Gilson, 1990; Richter, Bengen, Alsup, Brunn, Kilcayne, Challenon, 1974; Love, Gardner, 1992; La Familia Sana Program, 1992). In a health care system largely focused on acute care needs, the community-oriented approach of involving community lay health workers and volunteers must not be overlooked as a strategy for expanding access, reducing cost, and improving quality of care. These health workers have an important role to play as the health care system strives

to function efficiently, in serving underserved populations (Wimer, Siefer, Finocchio, et.al., 1995). Community lay health workers potentially offer a cost-effective mechanism to promote the appropriate use of breast health care resources. In comparison with traditional health care providers, they are relatively inexpensive to recruit, train, and supervise, thus reducing project cost. While they are by no means suggested to replace traditional breast health care providers, these workers can serve as partners or extensions of the breast health team, and can help prevent unnecessary reliance on costly specialty services (Knobel, 1992; Knobel, 1992; Levine, Becker, Bone, 1992).

Most important, however, is the potential impact generated from the pre-existing relationships these workers possess with their communities. Because they live in and are reflective of the community served, are low-income, and are in some cases, welfare recipients, these workers can be actively involved in the ongoing assessment of community health needs. They also reflect the linguistic and cultural diversity of the population served, and promote shared decision making among the program's governing body and staff (Wimer, Seifer, Finocchio, Leslie, et.al).

As the involvement of the CLHWs in the study increased, their self-esteem also increased. Each worker began to display a sense of pride and responsibility from being associated with the study, verbally expressing ownership in the project. They also established a comfort level about working with individuals with higher education and income levels than they themselves possessed.

In summary, the CLHWs value has been demonstrated through the BHES. CLHWs should be considered a potential player in the community-based health systems mission to serve low-income populations. The current health care reform environment presents a valuable opportunity to benefit from the contributions of community health volunteers and workers (Wimer, Seifer, Finocchio, Leslie, et al). In addition to their direct role in health care, community lay health workers and volunteers further other social agendas such as reducing unemploy-

ment, while also contributing to community empowerment and growth. Also, as they play a role in the translation process, they will contribute to increased detection of breast and cervical cancer, and to decreased rates of related risk factors such as cigarette smoking and non-compliance in screening. The CLHWs, as in the case of the MSM BHES Project, should become established partners with program and research administrators, and should be provided with financial incentives as well as opportunities for career and professional development.

Historically, partnerships have been formed between community-based care systems such as community and migrant health centers, homeless health care programs, and public health departments (Knobel, 1992). More recently, however, as in the case of the MSM BHES, academic medical centers and managed care organizations have begun to develop partnerships with community residents to address, head on, health issues among low-income populations (Braithwaite, Murphy, Lythcott, Blumenthal, 1989; Richter, Bengen Alsop, et.al., 1974; Knobel, 1992).

The strength of the CLHWs in breast health programs can be the workers flexibility in finding creative solutions to changing community health needs. Traditionally, rigid program and provider criteria structures and other economic restrictions has inhibited this creativity, thereby minimizing the effectiveness of public health programs.

ACKNOWLEDGMENTS

This work was supported by the U.S. Army Medical Research and Materiel Command under DOD DAMD-17-94-J-4134.

We would also like to thank Bridget J. Toodle, of the National Black Leadership Initiative on Cancer and Keisha Marshall, Southeastern Primary Care Consortium, Inc. for their outstanding administrative secretarial support in making the Breast Health Education Study a success.

REFERENCES

- U.S. Department of Health & Human Services, (1991). *Alaska Community Health Aide Program Description* (Indian Health Service) (PHS 91-50212) Washington, D. C.
- A Leacon of Lay Health Worker Terms.: *La Familia Sana Program*., (1992), Hood River. Oregon.
- Allen, L., & Britt, D.W., (1983) Black women in American society: A resource development perspective. *Issues in Mental Health Nursing* 5(4), 61-79.
- Baquet, C., Ringer, K., & Young, J., (1986). *Cancer among Blacks and other Minorities Profiles*, National Cancer Institute, (NIH Publication Number 86-2785)
- Sung, J.F.C., Coates, R.J., Williams, J.E., Liff, J.M., Greenberg, R.S., Avery, B., & Blumenthal, D.S., McGrady, G. A. (1992). Avoidable Mortality from Cancer in Black Populations—Cancer Screening Intervention in Black Women in an Inner-City Atlanta., *Public Health Reports* 107(4) 381-388.
- Blumenthal, D.S., Sung, F.C., Williams, J., Coates, R., and Liff, J., (1993), Recruitment and Retention of Subjects in a Community-Based Cancer Prevention Project, Health Services Research, *Final Report of NCI NOI-CN-65032*, Morehouse School of Medicine, Atlanta, GA.
- Braithwaite, R.L., Murphy, F.G., Lythcott, N., & Blumenthal, D.S. 1989., Community Organization and Development for Health Promotion Within an Urban Black Community: A Conceptual Model. *Health Education* 20, (5) 56-60.
- Burack, R.C., Liang, J., (1989) The acceptance and completion of mammography by older black women. *American Journal of Public Health* 79, 721-726.
- American Cancer Society, *Cancer Facts & Figures*, (1991), Atlanta, GA.
- Farley, T., Flannery, J.T., (1989). Late-stage diagnosis of breast cancer in women of lower socioeconomic status: Public health implications. *American Journal of Public Health*, 79, 11508-1512 .
- Freeman, H., Wasfie, T., (1989), Cancer of the breast in poor Black women . *Cancer*, 63, (112) 2562-2569
- Giblin PT., (1989), Effective utilization and evaluation of indigenous health care workers. *Public Health Reports*, 104, 361-367.
- U.S. Department of Health & Human Services (1990). *Healthy People 2000 : Objective for the Nation: National Health Promotion and Disease Prevention Objectives* (PHS Publication Number 91-50212). Washington, DC.
- Kaiser Commission on the Future of Medicaid: Health Reform Legislation, (1994): *Comparison of House of Senate Majority Leadership Bills*; (DHHS Publication Number OHPAR 3-94). Washington, D.C.
- Kaiser Permanente, (1992), *Case management in Kaiser Permanent's Medicaid program in Hawaii*. Report of New Visions Conference, Oakland, CA.
- Kaiser Permanente, (1992), *Medicaid and managed care with Kaiser Permanente in Hawaii*. Report of the Conference on Medi-Cal and Managed Care, Sacramento, CA.
- Levine D., Becker D., & Bone LR., (1992), Narrowing the gap in health status of minority populations: a community-academic medical center partnership. *American Journal of Preventive Medicine*. 8 , 319-323.
- Love, M.B., Gardner, K., (1992) *The Emerging Role of the Community Health Worker in California*, Center for Health Promotion, San Francisco, CA.
- O'Neil, E.H., (1993) *Health Professions Education for the Future: School in Service to the Nation*, Pew Health Professions Commission: San Francisco, CA:
- Recommendations to improve access to Health Care through Physicians Work Force Reform, (1994), *Council on Graduate Medical Education*, Washington, D.C.
- Richter, R.W., Bengen B., Alsup, P.A., Brunn B., *Kilkayne, M.M., Challenon B.D. (1974), The Community health worker: A resource for improved health care delivery. *American Journal Public Health*, 64, 1056-1061.
- Thompson, G., Kessler, L.G., Boss, L.P. (1989), Breast cancer screening legislation in the United States: A commentary. *American Journal of Public Health*., 79, 1541-1543.
- Walt, G., Gilson, L. (1990). Community Health Workers in National Programmes: Just Another Pair of Hands? Philadelphia, PA: Open University Press.
- Wimer, A., Seifer, S.D., Finocchio, L., Leslie, J., O'Neil, E.H. (1995) Community Health Workers: Integral Members of the Health Care Work Force. *American Journal of Public Health*, 85, 1055-1058